CABINET FOR HEALTH AND FAMILY SERVICES

Department for Public Health [~~Commission for Children with Special Health Care Needs~~}

Division of Adult and Child Health Improvements [~~Health and Development Division~~]

(Emergency Amendment)

911 KAR 2:120E. Kentucky Early Intervention Program evaluation and eligibility.

RELATES TO: KRS 200.654, 34 C.F.R. 303.11, 303.300, 303.322, 20 U.S.C. 1471 to 1476

STATUTORY AUTHORITY: Executive Order 2004-444,KRS 194A.030(7), 194A.050, 200.660(7), 200.650-676, 34 C.F.R. 303.322, 20 U.S.C. 1474, 1475(a)(10)

NECESSITY, FUNCTION, AND CONFORMITY: Executive Order 2004-444 reorganized the Cabinet for Health and Family Services and placed the Department for Public Health under the Cabinet for Health and Family Services. KRS 200.660 requires the Cabinet [~~for Health Services~~] to administer funds appropriated to implement the provisions of KRS 200.650 to 200.676, to enter into contracts with service providers, and to promulgate administrative regulations. This administrative regulation establishes the evaluation and eligibility requirements for First Steps, Kentucky's Early Intervention Program.

Section 1. Evaluation.

(1) (a) A child referred to the First Steps Program shall be initially evaluated to determine eligibility when

1. the screen indicates a developmental delay; or

2. the screen does not indicate a delay, but the family still has concerns; and

3. the child does not have an established risk condition

(b) A child with established risk as listed in Section 2 (3)(b) shall receive a five (5) area assessment done by a Primary Level Evaluator in lieu of a Primary Level Evaluation. If a child is eligible due to an established risk condition of hearing loss, the five (5) area assessment shall be performed by a speech therapist or a teacher of the deaf and hard of hearing who is approved as a Primary Level Evaluator. [~~Beginning with annual IFSP meetings scheduled on or after January 1, 2004, the child shall be evaluated on an annual basis to determine on-going eligibility and to evaluate progress while in the program, until the child exits the program and in accordance with subsection (8) of this section.~~]

(2) (a) A determination of initial eligibility pursuant to Section 2 of this administrative regulation, assessments in the identified area of delay, in accordance with 911 KAR 2:130, and the initial IFSP team meeting shall occur within forty-five (45) calendar days after a point of entry receives an initial referral.

(b) If a determination of initial eligibility, assessments and initial IFSP team meeting does not occur within forty-five (45) calendar days due to illness of the child or a request by the parent, the delay circumstances shall be documented.

(c) If a family is referred for a determination of initial eligibility and the family is under court order or a social services directive to enroll their child in First Steps, the court or social service agency shall be informed within three (3) working days by the initial service coordinator, if the family refuses the determination of eligibility.

(3) Child records of evaluations transferred from an in-state or out-of-state developmental evaluator shall be reviewed by the initial service coordinator and shall be utilized for eligibility determination if:

(a) The records meet First Steps evaluation time lines established in subsection (4)(a) of this section; and

(b) The records contain the developmental evaluation information established in subsection (11)(a) and (b) of this section.

(4) The primary level evaluation [~~shall be the first level in the First Steps evaluation system and~~] shall be utilized to determine eligibility of children without established risk, developmental status and recommendations for further assessment to determine program planning.

(a) If there is a previous primary level evaluation available, it shall be used to determine eligibility if:

1.a. For children under twelve (12) months of age, the evaluation was performed within three (3) months prior to referral to First Steps; or

b. For children twelve (12) months to three (3) years of age, the evaluation was performed within six (6) months prior to referral to First Steps; and

2. There is no additional information or the family has not expressed new concerns that would render the previous evaluation no longer valid.

(b) If there is a previous primary level evaluation available that was performed within the timeframes established in subparagraph 1 of this paragraph but there are new concerns that shall render the evaluation no longer valid, the initial service coordinator shall request a new primary level evaluation.

(c) Primary level evaluations shall provide evaluation in the five (5) developmental areas identified in Section 2(1)(c)1 through 5 of this administrative regulation using norm-referenced standardized instruments that provide a standard deviation score in the total domain for the five (5) areas.

(d) The primary level evaluation shall be provided by:

1. A physician or nurse practitioner; and

2. A primary evaluator approved by the cabinet.

(e) A primary level evaluation shall include:

1. A medical component completed by a physician or a nurse practitioner that shall include:

a. A history and physical examination;

b. A hearing and vision screening; and

c. A child's medical evaluation that shall be current in accordance with the EPSDT Periodicity Schedule; and

2. A developmental component completed by a cabinet-approved primary level evaluator that utilizes norm-referenced standardized instruments, the results of which shall:

a. Include the recommendation of a determination of eligibility or possible referral for a record review; and

b. Be interpreted to the family prior to the discussion required by subsection (5) of this section.

(5)(a) Prior to the initial IFSP team meeting, the initial service coordinator shall

contact the family and primary level evaluator to discuss the child's eligibility in accordance with subsection (4)(e)2b of this section. If the child is determined eligible, the service coordinator shall:

1. Make appropriate arrangements to select a primary service coordinator;

2. Arrange assessments in the areas identified in Section 2(1)(c) of this administrative regulation found to be delayed; and

3. Assist the family in selecting service providers in accordance with 911 KAR 2:110. If the child is receiving therapeutic services from a provider outside of the First Steps Program, the service coordinator shall:

a. Invite the current provider to be a part of the IFSP team;

b. Request that the provider supply the team with his assessment and progress reports; and

c. If the current provider does not want to participate, have the First Steps provider consult with the current provider if assessing the area being treated by the current provider.

(b)1. If the child does not have an established risk condition identified in Section 2(1)(c) of this administrative regulation, and is determined not eligible, the team shall discuss available community resources, such as Medicaid, EPSDT, the Department for Public Health's and the Commission for Children with Special Health Care Need's (CCSHCN’s) Title V programs, and other third-party payors.

[~~2.a. If the child has an established risk condition, and the developmental evaluation does not indicate a developmental delay in at least one (1) skill area, the family shall receive service coordination services until the earlier of:~~

~~(i) An annual developmental evaluation that is performed in accordance with subsection (8) of this section; or~~

~~(ii) Notification that the family has a concern or suspects that the child may have a delay present that was not revealed by the testing.~~

~~b. If the situation described in clause a(ii) of this subparagraph occurs, the procedure established in Section 2(2) of this administrative regulation shall be followed.~~]

(6) At the initial IFSP team meeting, the IFSP team shall:

(a) Include the following members at a minimum:

1. The parent of the child;

2. Other family members, as requested by the parent, if feasible to do so;

3. An advocate or person outside of the family, if the family requests that the person participate;

4. The initial service coordinator;

5. The primary service coordinator;

6. A provider who performed an assessment on the child; and

7. If appropriate, a First Steps provider who shall provide services to the child or family;

(b) Verify the child's eligibility;

(c) Review the evaluation information identified in subsection (4) of this section;

(d) Review the assessment reports in accordance with 911 KAR 2:130;

(e) Determine the family's outcomes, strategies and activities to meet those outcomes <u>as determined by the family's priorities and concerns</u>; and

(f) Determine the services the child shall receive in order for the family to learn

the strategies and activities identified on the IFSP. This shall include identifying:

1. The discipline;

2. The professional, paraprofessional, or both;

3. The method in which services shall be delivered, such as individual, group, or both; ~~and~~

4. The payor source for the service; and

5. The frequency of the service.

(7)(a) Reevaluations shall be provided if the IFSP team determines a child's eligibility warrants review and the child does not have an established risk condition.

(b) Primary level reevaluations shall not be used to:

1. Address concerns that are medical in nature; or

2. Provide periodic, ongoing follow-up services for post-testing or testing for transition.

(c) Based on the result of the reevaluation or annual evaluation, the IFSP team shall:

1. Continue with the same level of services;

2. Continue with modified services; or

3. Transition the child from First Steps services.

~~[(8) The provisions of this subsection shall apply to annual IFSP meetings scheduled on or after January 1, 2004~~.

~~(a) In accordance with KRS 200.664(7), in order to determine on-going eligibility:~~

~~1. A developmental evaluation shall be performed on an annual basis no earlier than ninety (90) days nor later than sixty (60) days before the annual IFSP expiration~~

~~date,~~

~~2. An updated medical evaluation shall be obtained from the child's physician or nurse practitioner in accordance with subsection (4)(e)1c of this section.~~

~~(b) The annual developmental evaluation shall be performed by a primary level evaluator who is not currently providing a therapeutic intervention for that child and shall provide an evaluation in the five (5) developmental areas identified in Section 2(1)(c) of this administrative regulation.~~

~~(c) If the results of the annual evaluation do not meet the continuing program eligibility requirements of Section 2(4) of this administrative regulation, the service coordinator shall:~~

~~1. Within three (3) days of receiving the written evaluation report, notify the service provider of the results of the evaluation and that therapeutic intervention shall cease when the current IFSP expires;~~

~~2. Notify the family of the results of the evaluation and that when the current IFSP expires, the child and family are no longer eligible for First Steps services;~~

~~3. Facilitate a transition conference in accordance with 911 KAR 2:140, Section 1(14); and~~

~~4. Subsequent to the transition conference, discharge the child from the program.~~

~~(d) If the procedure established in Section 2(2) of this administrative regulation is administered, the service coordinator shall refer the information required by subsection (9)(b) of this Section to the record review team within five (5) workdays of receiving the annual evaluation results.~~

~~(e) If the results of the annual developmental evaluation meet the continuing~~

~~program eligibility requirements established in Section 2(4) of this administrative regulation, the IFSP team shall be convened for the annual IFSP meeting in accordance with 911 KAR 2:130, Section 2.~~]

(8) [~~(9)~~] A review of the child's First Steps record shall be the second level in the First Steps evaluation system that shall be utilized to determine eligibility, medical or mental diagnosis, program planning, or plan evaluation.

(a) Upon obtaining a written consent by the parent, a service coordinator shall submit a child's record to the Department for Public Health [~~CCSHCN~~] for a record review if:

1. A primary evaluator identifies a need for further developmental testing necessary to clarify a diagnosis to further define the child's developmental status in terms of a child's strengths and areas of need;

2. A child does not meet eligibility guidelines at the primary level, but an IFSP team member and the family still have concerns that the child is developing atypically and a determination of eligibility based on professional judgment is needed; or

3. The IFSP team requests an intensive level evaluation for the purposes of obtaining a medical diagnosis or to make specific program planning and evaluation recommendations for the individual child.

(b)1. If a service coordinator sends a child's record for a record review, the following shall be submitted to the Record Review Team [~~Committee~~], Department for Public Health, at the address indicated by the Department for Public Health. [~~Louisville CCSHCN office at 982 Eastern Parkway, Louisville, Kentucky 40217:~~]

a. A cover letter from the service coordinator or primary evaluator justifying the referral for a record review;

b. Primary level evaluation information specified in subsection (10) of this section;

c. Available assessment reports required in 911 KAR 2:130;

d. Available IFSPs and amendments;

e. Most recent progress reports from the IFSP team members. Reports older than three (3) months shall include an addendum reflecting current progress;

f. Therapeutic staff notes from the previous two (2) months; and

g. If requesting a record review for a child who is receiving speech therapy, a hearing evaluation performed by an audiologist within six (6) months of the request.

2. The service coordinator requesting the record review shall attempt to procure and submit the following information, if available:

a. Birth records, if neonatal or perinatal complications occurred;

b. General pediatric records from the primary pediatrician;

c. Medical records from hospitalizations; and

d. Records from medical subspecialty consultations, such as neurology, orthopedic, gastroenterology or ophthalmology.

(c)1. Upon receiving a referral, a Record Review Team [~~team of CCSHCN professional staff~~] shall conduct a record review.

2. After conducting the record review, the Record Review Team [~~CCSHCN staff~~] shall:

a. Determine whether there are at least sixty (60) calendar days from the date of the review before the child turns three (3) years of age;

b. Determine that the child meets or does not meet the eligibility criteria established in Section 2(1) of this administrative regulation; and

c. Provide the IFSP team with recommendations for service planning.

3. If there are at least sixty (60) calendar days from the date of the review before the child turns three (3) years of age, the Record Review Team [~~CCSHCN staff~~] shall:

a. Determine if further developmental testing, diagnostics or additional professional judgment are required in order to adequately ascertain the child's developmental needs; and

b. Refer:

(i) The child for an intensive level evaluation, the third level in the First Steps evaluation system; or

(ii) The family to local community resources.

4. If there are not at least sixty (60) calendar days from the date of the review before the child turns three (3) years of age, the Record Review Team [~~CCSHCN staff~~] shall provide the IFSP team with a recommendation for transition planning.

5. Upon the record review team reviewing the child's record, the team shall provide the family and service coordinator with a letter, within fourteen (14) calendar days of the review, informing them of the information described in this paragraph

(d) Intensive level evaluations are conducted by one or more of the following as determined by the Department for Public Health approved Record Review

Team: [~~Upon request of the CCSHCN, a team approved by the CCSHCN and consisting of the following members shall perform an intensive level evaluation:~~]

1.a. A board certified developmental pediatrician;

b. A pediatrician who has experience in the area of early childhood development;

c. A pediatric psychiatrist; or

d. A pediatric neurologist; or [~~and~~]

e. [~~2.a.~~] One (1) or more developmental professionals identified in 911 KAR 2:150, Section 1; or

f. [~~b.~~] If an IFSP is currently in place, a developmental professional representing each discipline that is currently on the IFSP in addition to a professional whose scope of work addresses additional concerns expressed by the Record Review [~~intensive level evaluation~~] team.

(9) [~~(10)~~] Family rights shall be respected and procedural safeguards followed in providing evaluation services.

(a) Written parental consent shall be obtained before conducting an evaluation or assessment by the evaluator or assessor respectively.

(b) If a parent or guardian refuses to allow a child to undergo a physical or medical examination for eligibility because of religious beliefs:

1. Documentation shall be obtained in the form of a notarized statement. The notarized statement shall be signed by the parent or guardian to the effect that the physical examination or evaluation is in conflict with the practice of a recognized church or religious denomination to which they belong;

2. If a child is determined to be eligible, First Steps shall provide, at the parent's request, services that do not require, by statute, proper physical or medical evaluations; and

3. The initial service coordinator shall explain to the family that refusal due to religious beliefs may result in a denial of services which require a medical assessment on which to base treatment protocols.

(10) [~~(11)~~] A report shall be written in accordance with the time frames established in paragraph (c)1 of this subsection upon completion of each primary level and intensive level evaluation.

(a) A report resulting from a primary level evaluation or an intensive level evaluation shall include the following components:

1. Date of evaluation;

2. Names of evaluators and those present during the evaluation, professional degree, and discipline;

3. The setting of the evaluation;

4. Name and telephone number of the contact person;

5. Identifying information that includes the:

a. Child's CBIS identification number;

b. Child's name and address;

c. Child's chronological age (and gestational age, if prematurely born) at the time of the evaluation;

d. Health of the child during the evaluation;

e. Date of birth;

f. Referral source; and

g. Reason for referral or presenting problems;

6. Tests administered or evaluation procedures utilized and the purpose of the instrument. One (1) method of evaluation shall not be used, but a combination of tests and methods shall be used;

7. Test results and interpretation of strengths and needs of the child;

8. Test results reported in standard deviation pursuant to subsection (4)(e)2 of this section;

9. Factors that may have influenced test conclusion;

10. Eligibility;

11. Developmental status or diagnosis;

12. Suggestions regarding how services may be provided in a natural environment that address the child's holistic needs based on the evaluation;

13. Parent's assessment of the child's performance in comparison to abilities demonstrated by the child in more familiar circumstances;

14. A narrative description of the five (5) areas of the child's developmental status;

15. Social history;

16. Progress reports, if any, on the submitted information; and

17. A statement that results of the evaluation were discussed with the child's parent.

(b) The report required by paragraph (a) of this subsection shall be written in clear, concise language that is easily understood by the family.

(c)1. The reports and notification of need for further evaluation shall be made available to the current IFSP team and family within fourteen (14) calendar days from the date the evaluator received the complete evaluation referral.

2. In addition to the requirements established in this section, an intensive level evaluation site shall:

a. Provide to the Record Review Team [~~Committee~~] a copy of the evaluation report within fourteen (14) calendar days from the date the evaluator received the evaluation referral; and

b. If an IFSP is currently in place:

(i) Focus recommendations on areas that are specified on the IFSP as being of concern to the family;

(ii) Identify strategies and activities that would help achieve the outcomes identified on the IFSP; and

(iii) Provide suggestions for the discipline most appropriate to transfer the therapeutic skills to the parents.

3. If it is not possible to provide the report and notification required in this paragraph by the established time frame due to illness of the child or a request by the parent, the delay circumstances shall be documented and the report shall be provided within five (5) calendar days of completing the evaluation.

Section 2. Eligibility. (1) Except as provided in subsection (2) or (3) of this section, a child shall be eligible for First Steps services if he is:

(a) Aged birth through two (2) years;

(b) A resident of Kentucky at the time of referral and while receiving a service;

(c) Through the evaluation process determined to have fallen significantly behind developmental norms in the following skill areas:

1. Total cognitive development;

2. Total communication area through speech and language development, which shall include expressive and receptive;

3. Total physical development including growth, vision and hearing;

4. Total social and emotional development; or

5. Total adaptive skills development; and

(d) Significantly behind in developmental norms as evidenced by the child's score being:

1. Two (2) standard deviations below the mean in one (1) skill area; or

2. At least one and one-half (1 1/2) standard deviations below the mean in two (2) skill areas.

(2)(a) If a norm-referenced testing reveals a delay in one (1) of the five (5) skill areas but does not meet the eligibility criteria required by subsection (1)(d) of this section, a more in-depth standardized test in that area of development may be administered if the following is evident:

1. The primary level evaluator, service coordinator or the family has a concern or suspects that the child’s delay may be greater than the testing revealed;

2. A more sensitive norm-referenced test tool may reveal a standardized score which would meet eligibility criteria; and

3. There is one (1) area of development that is of concern.

(b) Upon completion of the testing required by paragraph (a) of this subsection, the results and information required by Section 1(9)(b) of this administrative regulation shall be submitted by the service coordinator to the record review team for a determination of eligibility.

(3) A child shall be eligible for First Steps services if:

(a) The child is being cared for by a neonatal follow-up program and its staff determine that the child meets the eligibility requirements established in subsection (1) or (4) of this section; or

(b) Meets the criteria established in KRS 200.654(10)(b) who has one (1) of the following conditions diagnosed by a physician or advanced registered nurse practitioner (ARNP):

Aase-Smith syndrome
Aase syndrome
Acrocallosal syndrome
Acrodysostosis
Acro-Fronto-Facio-Nasal Dysostosis
Adrenoleukodystrophy
Agenesis of the Corpus Callosum
Agyria
Aicardi syndrome
Alexander's Disease
Alper's syndrome
Amelia
Angelman syndrome
Aniridia
Anophthalmia/Microphthalmia
Antley-Bixler syndrome
Apert syndrome
Arachnoid cyst with neuro-developmental delay
Arhinencephaly
Arthrogryposis

Ataxia
Atelosteogenesis
Autism
Baller-Gerold syndrome
Bannayan-Riley-Ruvalcaba syndrome
Bardet-Biedl syndrome
Bartsocas-Papas syndrome
Beals syndrome (congenital contractural arachnodactyly)
Biotinidase Deficiency
Bixler syndrome
Blackfan-Diamond syndrome
Bobble Head Doll syndrome
Borjeson-Forssman-Lehmann syndrome
Brachial Plexopathy
Brancio-Oto-Renal (BOR) syndrome
Campomelic Dysplasia
Canavan Disease
Carbohydrate Deficient Glycoprotein syndrome
Cardio-Facio-Cutaneous syndrome

Carpenter syndrome
Cataracts - Congenital
Caudal Dysplasia
Cerebro-Costo-Mandibular syndrome
Cerebellar Aplasia/Hypoplasia/Degeneration
Cerebral Atrophy
Cerebral Palsy
Cerebro-oculo-facial-skeletal syndrome
CHARGE Association
Chediak Higashi syndrome
Chondrodysplasia Punctata
Christian syndrome
Chromosome Abnormality a.unbalanced numerical (autosomal) b. numerical trisomy (chromosomes 1-22) c. sex chromosomes XXX; XXXX; XXXXX; XXXY; XXXXY
CNS Aneurysm with Neuro-Developmental Delay
CNS Tumor with Neuro Developmental Dela
Cockayne syndrome

Coffin Lowry syndrome
Coffin Siris sydrome
Cohen syndrome
Cone Dystrophy
Congenital Cytomegalovirus
Congenital Herpes
Congenital Rubella
Congenital Syphilis
Congenital Toxoplasmosis
Cortical Blindness
Costello syndrome
Cri du chat syndrome
Cryptophthalmos
Cutis Laxa
Cytochrome-c Oxidase Deficiency
Dandy Walker syndrome
DeBarsy syndrome
DeBuquois syndrome
Dejerine-Sottas syndrome
DeLange syndrome
DeSanctis-Cacchione syndrome

Diastrophic Dysplasia
DiGeorge syndrome (22q11.2 deletion)
Distal Arthrogryrosis
Donohue syndrome
Down syndrome
Dubowitz syndrome
Dyggve Melchor-Clausen syndrome
Dyssegmental Dysplasia
Dystonia
EEC (Ectrodactyly-ectodermal dysplasia-clefting) syndrome
Encephalocele
Encephalo-Cranio-Cutaneous syndrome
Encephalomalacia
Exencephaly
Facio-Auriculo-Radial dysplasia
Facio-Cardio-Renal (Eastman-Bixler) syndrome
Familial Dysautonomia (Riley-Day syndrome
Fanconi Anemia
Farber syndrome

Fatty Acid Oxidation Disorder (SCAD, ICAD, LCHAD)
Femoral Hypoplasia
Fetal Alcohol syndrome/Effects
Fetal Dyskinesia
Fetal Hydantoin syndrome
Fetal Valproate syndrome
Fetal Varicella syndrome
FG syndrome
Fibrochondrogenesis
Floating Harbor syndrome
Fragile X syndrome
Fretman-Sheldon (Whistling Facies) syndrome
Fryns syndrome
Fucosidosis
Glaucoma - Congenital
Glutaric Aciduria Type I and II
Glycogen Storage Disease
Goldberg-Shprintzen syndrome
Grebe syndrome

Hallermann-Streiff syndrome
Hays-Wells syndrome
Head Trauma with Neurological Sequelae/Developmental Delay
Hearing Loss [(~~Bilateral permanent hearing loss with pure tone average of 30dB or greater)~~] (30dB or greater in better ear as determined by ABR audiometry or audiometric behavioral measurements)
Hemimegalencephaly
Hemiplegia/Hemiparesis
Hemorrhage-Intraventricular Grade III, IV
Hereditary Sensory & Autonomic Neuropathy
Hereditary Sensory Motor Neuropathy (Charcot Marie Tooth Disease)
Herrmann syndrome
Heterotopias
Holoprosencephaly (Aprosencephaly
Holt-Oram syndrome
Homocystinuria
Hunter syndrome (MPSII)

Huntington Disease
Hurler syndrome (MPSI)
Hyalanosis
Hydranencephaly
Hydrocephalus
Hyperpipecolic Acidema
Hypomelanosis of ITO
Hypophosphotasia-Infantile
Hypoxic Ischemic encephalopathy
I-Cell (mucolpidosis II) Disease
Incontinentia Pigmenti
Infantile spasms
Ininencephaly
Isovaleric Acidemia
Jarcho-Levin syndrome
Jervell syndrome
Johanson-Blizzard syndrome
Joubert syndrome
Kabuki syndrome
KBG syndrome
Kenny-Caffey syndrome

Klee Blattschadel
Klippel-Feil Sequence
Landau-Kleffner syndrome
Lange-Nielsen syndrome
Lanqer Giedion syndrome
Larsen syndrome
Laurin-Sandrow syndrome
Leber's Amaurosis
Legal blindness (bilateral visual acuity of 20/200 or worse corrected vision in better eye)
Leigh Disease
Lennox-Gastaut syndrome
Lenz Majewski syndrome
Lenz Microophthalmia syndrome
Levy-Hollister (LADD) syndrome
Lesch-Nyhan syndrome
Leukodystrophy
Lissencephaly
Lowe syndrome
Lowry-Maclean syndrome

Maffucci syndrome
Mannosidosis
Maple Syrup Urine Disease
Marden Walker syndrome
Marshall syndrome
Marshall-Smith syndrome
Maroteaux-Lamy syndrome (MPS VI)
Maternal PKU Effects
Megalencephaly
MELAS
Meningocele (cervical)
MERRF
Metachromatic Leukodystrophy
Metatropic Dysplasia
Methylmalonic Acidemia
Microcephaly
Microtia-Bilateral
Midas syndrome
Miller (postaxial acrofacial-Dysostosis) syndrome
Miller-Dieker syndrome

Mitochondrial Disorder
Moebius syndrome
Morquio syndrome (MPS IV)
Moya-Moya Disease
Mucolipidosis II, III
Multiple congenital anomalies (major organ birth defects)
Multiple Pterygium syndrome
Muscular Dystrophy
Myasthenia Gravis - Congenital
Myelocystocele
Myopathy - Congenital
Myotonic Dystrophy
Nager (Acrofacial Dysostosis) syndrome
Nance Horan syndrome
NARP
Neonatal Meningitis/Encephalitis
Neuronal Ceroid Lipofuscinoses
Neuronal Migration Disorder
Nonketotic Hyperglycinemia
Noonan syndrome

Ocular Albinism
Oculocerebrocutaneous syndrome
Oculo-Cutaneous Albinism
Optic Atrophy
Optic Nerve Hypoplasia
Oral-Facial-Digital syndrome Type I-VII
Osteogenesis Imperfecta Type III-IV
Osteopetrosis (Autosomal Recessive)
Oto-Palato-Digital Syndrome Type I-II
Pachygyria
Pallister Mosaic syndrome
Pallister-Hall syndrome
Pelizaeus-Merzbacher Disease
Pendred's syndrome
Periventricular Leukomalacia
Pervasive Developmental Disorder
Peters Anomaly
Phocomelia
Pierre Robin Sequence
Poland Sequence
Polymicrogyria

Popliteal Pterygium syndrome
Porencephaly
Prader-Willi syndrome
Progeria
Propionic Acidema
Proteus syndrome
Pyruvate carboxylase Deficiency
Pyruvate Dehydrogenase Deficiency
Radial Aplasia/Hypoplasia
Refsum Disease
Retinoblastoma
Retinoic Acid Embryopathy
Retinopathy of Prematurity Stages III, IV
Rett syndrome
Rickets
Rieger syndrome
Roberts SC Phocomelia
Robinow syndrome
Rubinstein-Taybi syndrome
Sanfilippo syndrome (MPS III)
Schinzel-Giedion syndrome

Schimmelpenning syndrome (Epidermal Nevus syndrome)
Schizencephaly
Schwartz-Jampel syndrome
Seckel syndrome
Septo-Optic Dysplasia
Shaken Baby syndrome
Short syndrome
Sialidosis
Simpson-Golabi-Behmel syndrome
Sly syndrome (MPS VII)
Smith-Fineman-Myers syndrome
Smith-Limitz-Opitz syndrome
Smith-Magenis syndrome
Sotos syndrome
Spina Bifida (Meningomyelocele)
Spinal Muscular Atrophy
Spondyloepiphyseal Dysplasia Congenita
Spondylometaphyseal Dysplasia
Stroke
Sturge-Weber syndrome

TAR (Thrombocytopenia-Absent Radii syndrome)
Thanatophoric Dysplasia
Tibial Aplasia (Hypoplasia)
Toriello-Carey syndrome
Townes-Brocks syndrome
Treacher-Collins syndrome
Trisomy 13
Trisomy 18
Tuberous Sclerosis
Urea Cycle Defect
Velocardiofacial syndrome (22q11.2 deletion
Wildervanck syndrome
Walker-Warburg syndrome
Weaver syndrome
Wiedemann-Rautenstrauch syndrome
Williams syndrome
Winchester syndrome
Wolf Hirschhorn syndrome
Yunis-Varon syndrome
Zellweger syndrome

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(4) A child shall have continuing program eligibility for First Steps services if the child is under three (3) years old, is a resident of Kentucky, and the results of the annual evaluation:

(a) Meet the initial eligibility requirements of subsections (1) to (3) of this Section; or

(b) Indicate a score of below one (1) standard deviation below the mean in at least one skill area that showed a previous score of at least one and one-half (1½) standard deviations below the mean in that same area.

(5) If a child referred to the First Steps Program was born at less than thirty-seven (37) weeks gestational age, the following shall be considered:

(a) The chronological age of infants and toddlers who are less than twenty-four (24) months old shall be corrected to account for premature birth. The evaluator shall ensure that the instrument being used allows for the adjustment for prematurity. If it does not, another instrument shall be used.

(b) Correction for prematurity shall not be appropriate for children born prematurely whose chronological age is twenty-four (24) months or greater.

(c) Documentation of prematurity shall include a physician's or nurse practitioner's written report of gestational age and a brief medical history.

(d) Evaluation reports on premature infants and toddlers shall include test scores calculated with the use of both corrected and chronological ages.

Section 3. Incorporation by Reference. (1) The Early, Periodic, Screening, Diagnostic and Treatment (EPSDT) Periodicity Schedule, August 2003 edition, is incorporated by reference.

(2) This material may be inspected, copied, or obtained, subject to applicable copyright law, at the Department for Public Health, 275 East Main Street, Frankfort, KY 40621, [~~Commission for Children with Special Health Care Needs, 982 Eastern Parkway, Louisville, Kentucky 40217,~~] Monday through Friday, 8 a.m. to 4:30 p.m.

911 KAR 2:120E. Kentucky Early Intervention Program evaluation and eligibility

Reviewed:

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Nickolas Z. Kafoglis, M.D.,Chair Date
Public Health Services Advisory Council

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Rice C. Leach, M.D. Date
Commissioner
Department for Public Health

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Dr. Duane Kilty Date
Undersecretary for Administration and Fiscal Affairs

APPROVED:

_____

James W. Holsinger, Jr., M.D. Date
Secretary

REGULATORY IMPACT ANALYSIS
AND TIERING STATEMENT

Administrative Regulation #: 911 KAR 2:120E
Cabinet for Health and Family Services
Agency: Department for Public Health
Contact person: Steve Davis, 502/564-2154

(1) Provide a brief summary of:
(a) What this administrative regulation does: This regulation allows the Cabinet to administer funds appropriated, to enter into contracts with service providers and amend the evaluation and eligibility requirements for First Steps, Kentucky's Early Intervention Program.
(b) The necessity of this administrative regulation: KRS 200.650 to 200.676 requires the Cabinet for Health and Family Services to administer First Steps, Kentucky's Early Intervention System.
(c) How this administrative regulation conforms to the content of the authorizing statutes: KRS 200.650 to 200.676 requires the implementation of funds for the provision of contract services, to promulgate regulations and to establish evaluation and eligibility requirements for the Kentucky Early Intervention Program.
(d) How this administrative regulation currently assists or will assist in the effective administration of the statutes: This amendment moves the First Steps program from the Commission for Children With Special Health Care Needs to the Department for Public Health and updates the First Steps Program to maintain and implement a statewide comprehensive system of early intervention services for infants and toddlers with disabilities and their families and to coordinate the payment for such services.

(2) If this is an amendment to an existing administrative regulation, provide a brief summary of:
(a) How the amendment will change this existing administrative regulation: Section 1(1)(b): The indications for an initial evaluation for a child referred to First Steps are clarified. The requirements for annual evaluations for on-going eligibility are changed. Section 1(4): The primary level evaluation is no longer required to be the first level in the evaluation system. The primary evaluation is required to determine eligibility of children without established risk. Section 1(5)(b): The requirement that the family receive service coordination services when no developmental delay is indicated, but the child has an established risk condition, is deleted. Section 1(6)(f): The Individual Family Service Plan (IFSP) Team is required to determine the frequency of the service.
Section 1(7)(a): Re-evaluations shall be provided if the IFSP Team determines the child's eligibility warrants review and the child does not have an established risk condition. Section 1(8)(a): Annual IFSP

meetings for determining ongoing eligibility are clarified. Section 1(8)(c): Three days are changed to five days for notification of evaluation results. Section 1(9)(a): CCSHCN is changed to lead agency. Section 1(9)(b): Record Review Committee is changed to Record Review Team and a new address is given. Section 1(9)(c): CCSHCN staff is changed to Record Review Team. Section 1(9)(d): Requirement that CCSHCN request an intensive level evaluation is deleted. Intensive level evaluations provider qualifications are clarified. Alphabetizing is corrected. Intensive level evaluation team is replaced by Record Review team.

(b)The necessity of the amendment to this administrative regulation: without this amendment, the regulation would not be in compliance with the Executive Order moving the First Steps program to the Department for Public Health and the First Steps Partnership Group recommendations would not be in effect.

(c) How the amendment conforms to the content of the authorizing statutes: This amendment carries out the intent and provisions of the authorizing statutes.

(d) How the amendment will assist in the effective administration of the statutes: Without this amendment the Executive Order and statutes cannot be enforced.

(2) List the type and number of individuals, businesses, organizations, or state and local governments affected by this administrative regulation: Over 600 contracted providers, which includes 2000 individuals that serves over 10,000 children with established risk diagnoses or developmental delays, and their families; and local communities or agencies that plan for, use, or develop community services for children with disabilities.

(3) Provide an assessment of how the above group or groups will be impacted by either the implementation of this administrative regulation, if new, or by the change if it is an amendment: Over 600 contracted providers which includes 2000 individuals that serves over 10,000 children with established risk diagnoses or developmental delays, and their families; and local communities or agencies that plan for, use, or develop community services for children with disabilities.

(4) Provide an assessment of how the above group or groups will be impacted by either the implementation of this administrative regulation, if new, or by the change if it is an amendment: These groups will be impacted by the changes to primary service coordination.

(5) Provide an estimate of how much it will cost to implement this administrative regulation:
(a) Initially: None
(b) On a continuing basis: None

(6) What is the source of the funding to be used for the implementation and enforcement of this administrative regulation: None

(7) Provide an assessment of whether an increase in fees or funding will be necessary to implement this administrative regulation, if new, or by the change if it is an amendment: None

(8) State whether or not this administrative regulation establishes any fees or directly or indirectly increases any fees: None

(9) TIERING: Is tiering applied? (Explain why tiering was or was not used)
Tiering was not appropriate in this administrative regulation because the administrative regulation applies equally to all those individuals or entities regulated by it